

HIV Is a Story First Written on the Bodies of Gay and Bisexual Men

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See also Morabia, p. 1175, Landers et al., p. 1180, and the HIV/AIDS and Our World: 1981–2021 section, pp. 1231–1266.

Whatever else it may be, AIDS is a story, or multiple stories, and read to a surprising extent from a text that does not exist: the body of the male homosexual.¹

In 1980, Ken Horne, a gay sex worker in San Francisco, California, became the first person to be diagnosed with acquired immune deficiency syndrome (AIDS) in the United States.² A year later, the Centers for Disease Control and Prevention's (CDC's) *Morbidity and Mortality Weekly Report* described five cases of *Pneumocystis pneumonia* among young "homosexual" men living in Los Angeles, California.³ By 1982, the term "gay-related immune deficiency" gained traction in the media and among health care professionals to describe the assumed inherent link between homosexuality and what would later be known as human immunodeficiency virus (HIV).⁴ The term "gay-related immune deficiency" reflected homophobic ignorance and the dearth of epidemiologic evidence that existed at the time. In 1983, frustrated by their shared experiences of stigma, gay men with AIDS at the Fifth Annual Gay and Lesbian Health

Conference brought forth the Denver Principles, which catalyzed self-empowerment across health movements for decades to come.

As significant as these time markers are, the HIV story in the United States likely dates back two or more decades before the 1980s. Robert Rayford, a Black adolescent who grew up in the Old North neighborhood of St. Louis, Missouri, died of pneumonia in 1969, after enduring a severe chlamydia infection and Kaposi's sarcoma. In 1987, western blot postmortem testing on Rayford's tissue samples confirmed HIV infection. Although we may never know for certain, Rayford may have contracted HIV selling sex or, like too many gay and bisexual youths worldwide, because he was the target of sexual violence.⁵

These early events remind us that HIV is a story first written on the bodies of gay and bisexual men. And the goal of this editorial commemorating the first published cases of AIDS is to underscore the critical importance of human rights for sexual minority men and women and as the basis of the HIV response.

HIV AMONG GAY AND BISEXUAL MEN

Race, class, and sexual orientation continue to shape the HIV epidemic in the United States and around the world, with new infections disproportionately affecting men who have sex with men in Black and Brown communities. Globally, from 2010 to 2019, HIV diagnoses increased by 25% among gay and bisexual men, even as infections in other groups declined.⁶ In the United States, gay and bisexual men make up nearly 70% of all new HIV diagnoses each year; among them 31% are Black and 25% are Latinx.⁷

Reliably collected epidemiologic evidence continue to tell a story that centers the HIV pandemic on gay and bisexual men, yet public health agencies continue to resource HIV responses cast broadly to the "general population."⁸ Adopting HIV responses geared toward the general population (as opposed to carefully targeted strategies that are commensurate with epidemiologic trends) is a discursive public health norm that often presumes groups are heterosexual, cisgender, able bodied, socioeconomically secure, and—in the Global North—White.⁹ As a result, HIV services are rendered difficult to safely access for those in need and most marginalized.

COMMUNITY-LED HIV RESPONSES

Building on the civil rights, women's rights, and gay and lesbian liberation movements in the United States, lesbian, gay, bisexual, transgender, queer (LGBTQ) people, and their allies worked together to establish HIV service organizations even as governments struggled to respond.¹⁰ In 1986, Craig Harris, a

Black gay man living with HIV, stormed the stage of the American Public Health Association (APHA) annual convention. Harris and other activists were frustrated that there were no people of color scheduled to speak at the first APHA plenary on HIV.¹¹ Actions like Harris' gave rise to community-led service and advocacy organizations. These organizations brought community members living with and affected by HIV at the grassroots level into the non-profit industry, often providing job security, decent wages, health care coverage, and dignity. Community members developed and implemented programs that were most culturally appropriate to their needs. These same organizations also played a critical role in safeguarding an increasingly visible LGBTQ community.

HIV activism has been integral to politicizing gay and bisexual men because the homophobia and HIV-related stigma they have experience at individual, community, and institutional levels are interlocked. Founded in 1986 and 1987, respectively, the Global Network of People Living with HIV and AIDS Coalition to Unleash Power were global activist groups with large LGBTQ contingents, central in determining strategy, deliberating scientific updates, and organizing protests. In addition, gay bars and businesses were involved in a range of HIV activism, including safer sex education and fundraising to cover the daily living and funeral costs of gay and bisexual men dying from AIDS. This model of power sharing was pioneered in the early years of the HIV response and subsequently enshrined in 1994 as the Meaningful Involvement of People living with HIV. Sadly, its principles have been eroding, as the HIV response was corporatized and HIV organizations and planning bodies began viewing people

living with HIV as passive recipients or "consumers" of services.

The advent of antiretroviral treatment in 1996 transformed the HIV response. Although universally embraced as a hard-fought achievement, biomedical advances in the prevention and treatment of HIV can inadvertently mask social drivers of the epidemic and keep people living with and affected by HIV in narrowly defined roles (e.g., outreach workers or peer educators). This is because a biomedicalized HIV response situates power with the clinician and trained professional. Community members are often the lowest paid but hardest working—the last hired and first fired. They are also repeatedly the last involved in decision making, thereby entrenching power differentials between those who determine what services and programs are needed and those who use them.¹² HIV funding has incrementally shifted away from community mobilization, social support, and advocacy and toward clinics meant to make access to antiretroviral treatment easier. The HIV sector has become beholden to clinics and their funders. Ironically, access to culturally appropriate health care remains difficult for people living with and disproportionately affected by HIV, including gay and bisexual men, even with the proliferation of clinics.⁶

HIV has also ravaged gay and bisexual men's communities. The high death rate in the early epidemic was concentrated largely among four intersecting groups: transgender people, sex workers, people who use drugs, and gay and bisexual men. This had a devastating impact on activism and community organizations, especially in Black and Brown communities, as people died, burned out, or otherwise left in mourning. Their absence hollowed the HIV

response, as cultural, community, and political programs they led in coalition with one another closed. Gay and bisexual men carry the burden of this community trauma, one that is often unaddressed because of public amnesia, HIV-related stigma, homophobia, gender inequities, racism, and classism.¹¹

A HUMAN RIGHTS LENS

Economic disenfranchisement, racism, gender inequality, and homophobia, codified in laws and policies, have limited the provision and uptake of HIV services.¹³ Same-sex sexual behavior, sex work, and drug use are criminalized in 68, 48, and 85 countries, respectively. Eighty-nine countries have laws that specifically criminalize HIV transmission, exposure, or nondisclosure.¹⁴ Thirty-seven US states still criminalize people living with HIV, and these laws disproportionately affect economically poor people, Black and Brown people, and gay men.¹⁵ Such laws encourage violence, discrimination, and stigma, which worsen health- and HIV-related racial/ethnic disparities among gay and bisexual men.

Human rights violations experienced by young gay and bisexual men are exacerbated by legal and policy barriers embedded in social values. For instance, laws requiring parental consent for health services and policies curtailing comprehensive sex education restrict access to sexual health services that LGBTQ youths need. Similarly, the dearth of legal protections for gender nonbinary or transgender people results in discriminatory gender policies and practices at clinics and service organizations, hindering access and exacerbating health disparities.¹⁴

A common thread that runs through the human rights abuses described here is a lack of respect for and protection of bodily autonomy and integrity. Bodily autonomy and integrity are sacrosanct. This means all people, including gay and bisexual men, have agency and autonomy over their own bodies. It also means that all people have the right to be self-determining; be secure from violence, including sexual assault; and have opportunities for sexual satisfaction, pleasure, and reproductive choice. Public health responses to the HIV and overall health needs of gay and bisexual men are too often designed and enacted solely with a disease containment focus and without serious consideration for these fundamental human rights principles.

CONCLUSIONS

After 40 years, not only do power inequities and HIV disparities remain, but they have also deepened, particularly for gay and bisexual men of color. Community-led action to eliminate racism, classism, gender inequalities, and homophobia are necessary in addressing structural barriers to services, which fuel persistent HIV disparities. Creative approaches to foster power sharing are also needed in the development and delivery of biomedical interventions. Finally, trauma-informed community reparations must be integral to all public health HIV responses. This includes funding for rights-based, evidence-informed, community-led programs that actively affirm the lives and histories of gay and bisexual men. **AJPH**

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CONFLICTS OF INTEREST

The authors have no conflicts of interest to declare.

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